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POINTS OF VIEW

What's in a Name? Alternatives to Learning Disability

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What's in a name? Alternatives to "Learning Disability"

Simon Whitaker

Abstract

The term learning disability is currently used in the UK to describe people who require a service due to a low intellectual ability. It is argued that the term is demeaning, confusing and, as currently defined, fails to describe the group of people to whom it is currently applied. It is suggested that a better term for researchers to use would be intellectual disability; however, we should avoid labelling individual services users at all.

Keywords: Learning Disability, Definitions, Labelling

Introduction

At a recent conference a service user challenged the speaker for using the term "Learning Disability", suggesting that it was an unpleasant term that the speaker would not like to apply to his children. It seemed that, for this service user at least, the label learning disability had acquired negative connotations. This may well be inevitable as it is just the latest term in a number that have been used over the years; previous ones have often been abandoned for being too demeaning. The most dramatic examples are "moron", "imbecile" and "idiot", technical terms used in the early part of the last century now used as words of abuse. The problem is that whatever name we use implies low intelligence, something that is looked down upon in current society. In addition to being demeaning, there are other concerns with the term that become apparent when one considers how it is currently defined.

Definition

The White Paper Valuing People (Department of Health 2001), which sets out the Government's vision for services for people with a learning disability, defines it as follows:

"1.5 Learning disability includes the presence of:

- A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with lasting effect on development."

(Valuing People 2001, Page 14).

It then goes on to clarify this:

"1.6 This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for

example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and community skills should also be taken into account when determining need.” (*Department of Health, Valuing People 2001, Pages 14 -15*).

Therefore, for a person to have a learning disability they must have an IQ<70 and additional deficits in adaptive behaviour. This leads to a number of problems with regard to how the term is understood and the extent to which we are able to identify these people with a learning disability.

Some Problems with the Definition

Learning disability is a confusing term

From the above definition it is clear that what people with learning disabilities have in common is a low intellectual ability, suggested to be an IQ<70. The definition therefore does not include people who have specific learning or intellectual problems such as dyslexia, or Attention Deficit Hyperactive Disorder (ADHD), unless the person has also got an IQ below 70. This is the source of a significant degree of confusion. In the United States as well as other countries, the term learning disability refers exclusively to specific learning problems such as dyslexia together with an IQ greater than 70. The most common internationally used term for people who have IQ<70 is “mental retardation”. This means that if, for example, a researcher in the UK wanted to look at the literature on, say, schooling for people with learning disabilities and typed the key words “learning disabilities” and “schooling” into a search engine they would get back papers on the education of children with specific learning disabilities. Papers written in the UK using the term “learning disability” will only be picked up by researchers in the US who are interested in specific learning disabilities and so may not be read by the people who need to read them. This confusion not only applies to researchers but also to other service providers who may feel that learning disability services are for people with specific learning disability and make inappropriate referrals.

We cannot measure IQ with sufficient accuracy

Although the above definition of learning disabilities does not give clear guidance as to how impaired social functioning should be, it does suggest that the IQ should be below 70. However, Whitaker (2003) has pointed to a number of reasons why IQ cannot be measured with sufficient accuracy for it to be used as a defining criterion for a learning disability. First, even the most well standardised tests of intelligence do not measure intelligence to within one IQ point. The commonly used Wechsler assessments only measure to an accuracy of between 4 and 6 IQ points. According to the WAIS-III manual (Wechsler 1997), it is not until a client scores an IQ of 64 or below that one can be 95% certain that they have an IQ below 70, and it is not until they score an IQ of 74 or above that one can be 95% certain that they have an IQ of 70 or above. Therefore, people in the IQ range 65 to 73 are in an ambiguous learning disability range, which, if we assume that IQs as low as 65 are normally distributed with a mean of 100 and a standard deviation of 15, is about 3% of the population as a whole. However, even if

we take into account that there are more people with IQs below 65 than would be predicted by this normal distribution (c.f. Whitaker 2005), there would only be 0.5% of the population with IQ<65. Therefore only 0.5% of the population would have a clear learning disability, one-sixth of the number who have an ambiguous learning disability.

Second, the IQ of the population as a whole is increasing by about 3 IQ points a decade (Flynn 1984, 1985, 1987, 1998, 2000). Therefore tests that were standardised several years ago would give higher IQ than tests standardised today. This raises the question as to whether the criterion IQ level should still be 70 on a test standardised some years ago, or whether it should be a reduced figure which takes account of the expected increase in IQ that would have occurred since the test was standardised. It seems to me that to be consistent it should be the latter. The problem, however, is that we do not know exactly how many points the score on a currently used IQ test should be decreased by to be equivalent to an IQ of 70 on a newly standardised test. This adds further error and ambiguity to the assessment of IQ.

Thirdly, there may be a major lack of consistency between different tests of intelligence in the lower IQ ranges. For example, a client could be found to have an IQ below 70 on one test and an IQ above 70 on another test. Both Flynn (1985) and Spitz (1986; 1989) reported the Wechsler Intelligence Scale for Children – Revised (WISC-R) scores 16-year-olds as having IQ up to 15 IQ points lower than the Wechsler Adult Intelligence Scale – Revised (WAIS-R), for IQs of 70 and below. It is therefore clear that either one or both of these tests is failing to produce an accurate measure of IQ. Although the revised versions of the Wechsler tests are not the latest standardisations, I am not aware of any empirical comparison between the new standardisation of these tests (the WAIS-III and WISC-IV) in this IQ range, and preliminary analysis of the test items suggests that the WISC-IV is significantly more demanding than the WAIS-III (Whitaker submitted). It therefore seems likely that this discrepancy still occurs. This uncertainty means that a measured IQ of 70 on the WAIS-III could correspond to a true IQ of between 75 and 55, and a measured IQ of 70 on the WISC-IV to a true IQ of between 85 and 66. It seems to me that this and the other sources of error in the measurement of low levels of intelligence makes defining the condition in terms of a specific IQ figure inappropriate.

It does not describe the people for whom we provide services

The majority of the people who would meet the above definition have never been provided with a specialised service and may well not need to be. Valuing People gives the following estimates of the prevalence of learning disabilities in the population as a whole:

“1.8 Producing precise information on the number of people with learning disabilities in the population is difficult. In the case of people with severe and profound learning disabilities, we estimate that there are about 210,000: around 65,000 children and young people, 120,000 adults or working age and 25,000 older people. In the case of people with mild/moderate learning disabilities, lower estimates suggest a prevalence rate of around 25 per 1000 populations – some

1.2 million people in England.” (*Department of Health. Valuing People 2001, Page. 15*).

Combining the estimates of those with mild to moderate learning disabilities and those with severe and profound learning disabilities gives an estimate of about 3% of the population, which corresponds to the number of people in the population who would expected to have IQ<70 (Whitaker 2005). This suggests that the second criterion of a reduced ability to cope independently is not very harsh. However, it is considerably greater than the number of people in the population who have a learning disability label and are known to services, which is only about 0.3% of the population (Whitaker 2004). There are therefore about nine times more people with unidentified learning disabilities than are currently known to services.

People with identified learning disabilities may differ from those with unidentified disabilities in a number of significant ways:

First, my experience of giving IQ tests over the last 25 years suggests that a number of people who have acquired a learning disability label have IQs above 70 and as such would not fit the above definition. Second, it seems likely that people with an identified learning disability have a greater degree of need or are less able to cope than the bulk of people who would fit the Valuing People definition. This is because the most common reason people are identified as having a learning disability is that they are found not to be able to cope in some respect, for example failing at school, failing to parent appropriately. The factor that these people have in common therefore is a need for a service, at some point in their lives, in order to cope.

It seems that the term learning disability can be demeaning to the people to whom it is applied, confusing to professionals and researchers and, as it is currently defined, fails to describe the group of people who receive a specialised service. Can we do any better? My feeling is that we probably can but to do this we need to separate the way we apply the term in a research context from that used by service providers to describe the people they provide a service for.

Alternative Definitions

Researchers and students

Scientists, researchers and academics need a term that communicates to others who the participants in their studies are, a term that can be put into search engines and get back appropriate information, that can be used in the title of journals so that it is clear to potential readers what the journal is about and can be used to describe specialist university courses. There are a number of alternatives currently used in the research literature. As noted above, the most commonly used one is ‘mental retardation’. However, I’m not sure that as a descriptive term it is clear what it means and to me it sounds very demeaning. An alternative that is beginning to be used is ‘intellectual disabilities’. This term is used in the title of two leading U.K. based journals, the *Journal of Applied Research in Intellectual Disabilities* and the *Journal of Intellectual Disability Research*. It is increasingly being used in papers appearing in US based journals, for example the American Journal of Mental Retardation. It clearly indicates the common factor in the

people who are the subject of the study, that they have a low intellectual ability so should not be confusing to people not fully familiar with the detailed definition of the term. Also if it is used in a search engine it will produce papers about such people. It may therefore be appropriate for the editors of this and other journals to consider replacing the term learning disability in their title with intellectual disability and for higher education bodies to consider changing the names of specialised courses from learning disability to intellectual disability. However, I would not recommend that we should start to label our services as a service for people with intellectual disabilities or the people who receive such services as people with intellectual disabilities. The term still has the potential to be demeaning and not everybody with low intellectual ability will require a service. It also may be taken to imply that there should be an IQ level above which a service is not provided which I would want to avoid.

Services and services users

The challenge here is to produce a name and definition that describes the people who need and are entitled to a specialised service without giving them a demeaning label.

To get over the problem of a negative label I would suggest that we simply do not give people a label but rather define whom the specialised service is for and then give that service a neutral name. For example, I currently work in a community learning disability team, based at the Redhouse Unit (fictitious name), which could be renamed the Redhouse Service based at the Redhouse Resource Unit. Not having the term learning disability or intellectual disability in the title of the services would mean that there were no negative implications about the people using the services. If we need a general term for the people who use the service we could use the term "service user". There then remains the issue of defining whom the service is for.

Valuing People is somewhat confused about who we should be providing services to. It suggests that people with learning disability make up about 3% of the population and then specifies that its recommendations apply to "all" people with learning disabilities. This is not feasible: we do not know who most of these people are, and if we were to try to do find them to provide them with services we would quickly be overwhelmed. The people we do know about are those who have acquired the label of having a learning disability and who are currently receiving a specialised service or have had one in the past. I would propose that these are basically the people we should continue to be providing a service for and we need to find an appropriate definition.

One factor that has played a major part in the definition of learning disability, both in the definition used in *Valuing People* and in other definitions, is whether the client has an IQ<70. I feel that this is a mistake, in part because of the errors in the measurement of IQ at low levels outlined above; however, even if we could measure IQ to an accuracy of one IQ point, IQ 70 is still an arbitrary figure. It seems apparent from the disparity between the number of people we would expect to have IQ<70 and the number we know about, that the bulk of people with IQ<70 are probably coping with no difficulty. It is also clear that there are a number of

people with IQs above 70 who are not coping even though a significant factor in their inability to cope is their relatively low intellectual ability, possibly in combination with other factors such as an autistic spectrum disorder, which are more common in people with low IQs. I would therefore suggest that any definition should acknowledge that the service is for people with low intellectual abilities but should not specify an IQ figure.

The other defining factor that is specified in the Valuing People definition is the individual's need of a service in order to cope. I suggested above that this is the major factor that distinguishes 0.3% of the population who have a learning disability label from the 3% of the population with true IQs<70. An inability to cope, which can be rectified by a service, should therefore be a major part of any criteria for a service.

I would therefore suggest that we should specify that the specialist service should be for:

People who are in need of community care services by reason of intellectual and/or pervasive developmental disorders, who are suffering significant distress or are unable to take care of themselves or their dependents or unable to protect themselves or their dependents against significant harm or exploitation.

This description of the services is based on a definition of a Vulnerable Adult (Lord Chancellor's Department 1997), which specifies a client's assessed need and not on an arbitrary measure of intellectual ability. It does not label the client so there should be fewer negative connotations for a client in using the services. The description also specifies people with pervasive developmental disorders, which encompass autistic spectrum disorders. I have included this for a number of reasons: first, as autistic spectrum disorders are often seen in people with low intellectual abilities, any services specifically for people whose inability to cope is due to low intellectual ability will inevitably see a lot of people with autistic spectrum disorders. Second, it seems to me that it is often a combination of the low intellectual ability and the autistic spectrum disorder in the same individual that results in their not being able to cope and not one of the disorders specifically. It therefore seems to be a mistake to try to specify which disorder is responsible for the client not being able to cope. Third, both low intellectual ability and autistic spectrum disorders will often be lifelong conditions, but may only stop the individual coping at particular points in their lives. Fourth, as specific services for people, particularly adults, with autistic spectrum disorders are rare, it makes sense for them to be provided by a service that has experience of working with the condition.

Other Perspectives

One of the aims of this paper is to stimulate debate and hopefully prompt others to write papers in response. However, it is suggested that the points of view papers in this journal present more than one perspective. I have therefore endeavoured to get the views of both colleagues and services users. Professor Read and The Burton Street Project in Hillsborough, Sheffield, a group of adults with "learning disabilities" have both kindly provided comments on this paper that appear at the end together with

some further comments that came with those from the Burton Street Project. Professor Read writes both from the perspective of a Consultant Psychiatrist in Learning Disabilities and as a parent of a child with profound disabilities, the Burton Street Project from their perspective of people who receive a service. In addition to this, I have discussed the suggestions made above with colleagues and have examined the websites of organisations representing service users, including People First and Mencap, in order to get the views of service users.

A concern that many colleagues have put to me is that eliminating a specified IQ figure as a defining criterion makes the definitions imprecise and as far as services are concerned such a change may open the floodgates to a large number of referrals of people who previously would not have been eligible for a service. It is felt that that this would result in service providers becoming overwhelmed and people who traditionally had a service getting a reduced service or not getting a service at all. I would readily admit that the definition that I propose appears to be less precise than previous definitions making use of the concept of IQ. However, it is explicitly imprecise, which is an honest reflection of our current ability to assess people with low intellectual ability. The definition based on IQ, on the other hand, suggests that people can be categorised as having a learning disability or not on the basis of an IQ assessment and assessment of adaptive skills. However, in reality this cannot be done due to the error in the tests outlined above. In reality the definitions are just as imprecise as the one I propose but wrongly give the impression of precision, which could lead to decisions made with regard to diagnosis on the basis of IQ tests not to be questioned when they should be. The concern about an increased number of referrals is legitimate and needs addressing. I do not believe that these proposals would result in a significant increase in referrals. The criteria still specify low intellectual ability with the addition that the low IQ or a pervasive developmental disorder should be why they need services. Secondly, the service providers still have scope for limiting referrals by more precisely defining the degree of distress a referred client should be under before they are eligible for a service. However, before any changes are made there would need to be negotiation with other service providers to ensure that all individuals who need and are entitled to a service get one.

With regard to the views of services users, People First, a self-advocacy organisation for people with learning difficulties, state on their website (www.peoplefirst.org.uk/whoarewe.html) that they don't like labels as "they keep them down". This suggests they would be in favour of avoiding the labelling of clients as proposed in this paper. However, they then go on to say that they choose to use "learning difficulties", as it is a label that doesn't hurt them as much as other labels such as mental handicap, mental retardation, intellectually handicapped, or mentally subnormal. They therefore may be in favour of retaining some label that identifies them as a group.

Clearly this debate needs to continue. Evidence may need to be sought as to the possible effects of not labelling service users. Also service users need to be brought into the debate and their views sought in a systematic way. In the meantime I hope this paper will generate further ideas.

Editor's comments: the following end note is intended to provide a further and interesting point of view on the issues of labelling in services today

Further Comments on 'What's in a name?' by Professor Stephen Read, Psychiatrist in Learning disabilities and parent.

Redundant terms – or not?

It was in 1974 that the then Secretary of State for Health first publicly used the term 'learning disabled' to describe those previously called 'mentally handicapped'.

In 1989, with the new term well ensconced in common parlance in the UK, a professor of psychiatry said to me that he thought it was a bad term in that it failed adequately to describe such individuals (picking out only one attribute – that of a disability of learning), whereas 'mental handicap' implied a spectrum or panoply of disabilities.

I've thought about this since and can say that I disagree. Certain individuals may have a variety of disabilities, but the only one that is lifelong and ineradicable is the learning disability. It is the one that counts above all others. Other disabilities associated with learning disability are the result of psychiatric and medical disorders, and not of the learning disability itself. For this reason, because it is a core disability, I am in favour of its retention.

I've long said that the only real consequence of a pure learning disability is the difficulty or impossibility of getting a job – of being economically self-sufficient. Some societies consider that such individuals cannot compete economically, and offer social and educational services and enhanced health care. In the UK, learning disability is one of a number of disabilities, which entitle an individual to Disability Living Allowance. If the existence of learning disability is refuted, then hundreds of thousands may have no basis for a claim. This is a second reason for retaining learning disability as a useful concept.

But for those who are not learning disabled, the term 'borderline learning disability' has no validity, is unnecessary and brings into doubt skills and capabilities, which, though hardly won, may be proudly owned. There is no excuse for marginalisation. If the term 'borderline learning disability' were to fall into disuse, then those who have been so termed can be called 'normal' and they need to have no argument with the term 'learning disability'. Thus we can all get on with our lives without being distracted by nonsensical pseudo-concepts such as 'borderline learning disability'. It is a redundant term and should no longer be used.

Further comments on ‘What’s in a name? Alternatives to “Learning Disability” by the Burton Street Group

The paper was converted into an accessible format by Anna and discussed by members of an identity group for adults with learning disabilities at The Burton Street Project in Hillsborough, Sheffield. The points raised in the paper were discussed and this answer was negotiated between all members of the group and written up by Anna.

The group was opposed to any major change to the term “learning disability”. The term ‘intellectual disability’ was rejected on the grounds that it could not be understood and used by the very people it seeks to describe. Though the paper points out that the term ‘intellectual disability’ would be mostly utilised by researchers, it was felt by the group to be exclusive due to the difficulty of the terminology. Several members of the group are part of a research group themselves, and it was felt that research in this area should concentrate on becoming more inclusive rather than less. The need for a universal term that may be understood and used in research was agreed however.

The term ‘service users’ was unanimously rejected on the grounds that it was meaningless to both the community in which a person lives and the person themselves. The nature of this term was also seen to add to the construction of people with learning disabilities as passive, and needing help, rather than as active and involved members of the community, who have support needs. The group was definite that the point should be made that not all people with a learning disability use what could be traditionally described as ‘services’, and so would be left without a term to explain any needs or difficulties they had. Though it was agreed that labelling people might have negative connotations, the label of learning disabilities was also seen to be a useful tool by several members of the group. For example, a member of the public shouted at one person for cycling on the pathway. He stopped and explained he had a learning disability and was not able to ride on the road. In this instance the term ‘learning disability’ was meaningful to both the individual and the member of public, and accurately conveyed the person’s difficulties in a way that he felt did not demean him. Several other instances similar to this were also recounted where the term learning disability could be used to describe needs without inappropriate detail. For example, one member needed to phone an ambulance after becoming ill, and could not accurately answer all the questions they were asked. They were then able to inform the operator they had a learning disability, and so the operator made the questions more accessible.

The group also felt a sense of ownership over the term ‘learning disability’, as the term was described as a label that united a group of people rather than demeaned them. One person when asked said, ‘it’s none of their business what we’ve got’. As such, if the term is to change, people with learning disabilities themselves must be at the centre of the reform so that they are not further disempowered by it.

The point was also raised that it is not the label that demeans, rather it is the social view of learning disabilities. As such, any change of term will eventually incur similar negative stereotypes and will need further review. This group then suggests that research concentrates on improving the

social inclusion of learning disabilities rather than superficial changes to terminology.

The Group:

Gwenaelle Ambuhl, Amy Beresford, Peter Brownley, Steven Chamberlain, Douglas Coe, Natalie Collins, Noreen Faruga, Sarah Faulkner, Robert Frost, Andy Gibbs, Anna Haigh, Jeanette Hodgkinson, Sara Moore, John Newton, Jean Nsengiyumua, Margaret Senior, Dawn Shepherd, Neil Smith, Peter Smith and Russell Thompson.

Definitions and contexts: a commentary on What's in a name? Alternatives to "Learning Disability".

Suzie Beart & Tom Isherwood

The questions of definition and labelling that Whitaker raises are important and worthy of discussion. In this commentary we will assert that language is powerful as a determinant of experience; however *how* a group is talked about is more important than *what* name is used to distinguish a group of people. Also, whilst Whitaker's concerns regarding the tools of definition are clear, it is imperative that people in the group being defined appreciate the process of definition if they are to be engaged in the debate about their naming.

Problems inherent in definition

Categorisation of human social experience is fraught with difficulty. Learning disability is not a 'thing' that can be measured with confidence and consensus in the way that weight can (Rapley 2004). Intelligence Quotient (IQ) is a concept, a construction developed by psychometricians in the United States Military (Lezak 2004). Measuring human performance is an inexact science, recognised in concepts such as the Standard Error of Measurement (a calculation of the accuracy a test can be expected to have) that gives the range of IQ points that Whitaker describes with reference to the WAIS III (Wechsler 1997). Constructing continua of intelligence and functioning, and generating cut off points to divide those continua, is more than arbitrary; it is a function of the needs of a society to compartmentalise need and distress so it can marshal resources to deal with it. The definition of learning disability and its alternative terms (and the tools of measurement that are used) are currently the property of professions and services rather than those to whom the label is applied (Gillman, Heyman and Swain 2000).

There seems to be some confusion within Whitaker's article with regard to the definition of population rather than service provision. Within any population (e.g. older adults, people who use drugs and alcohol or people who hear voices) there will be a smaller number who are not coping in some way; it is *only* that subgroup that *any* health or social service will deal with. People with learning disabilities are more vulnerable to a number of particular causes of distress, including a range of abusive experiences and discrimination and they may be in greater need of a service; however it is

only through contact with education, health or social services that they are given 'the label'.

Terms and contexts

The choice of terminology to describe the group who are currently and generally called 'people with learning disabilities' is important and the confusion *is* regrettable, but on the whole this is manageable within academia and public services (though other journal editors have bowed to 'pressure', Gates 2006). However, more important than the label are the ways in which people are talked about; it is the language used around the term *in context* that matters most. One can use euphemisms such as describing services in terms of the buildings they occupy; yet this could appear apologetic or clandestine. It is how one talks about the experience and opportunities for that group that shape the ways in which society responds in relation to them. Discourses of inability and incapability allow a particular view of this group, discourses of positive contribution and achievements quite another. Professional discourses are invested with power by society at large (Parker 2002); therefore it is the responsibility of those professionals and service providers to be aware of the impact of all their language rather than just that of a singular term. This will affect whether the term is experienced as demeaning or not.

Ownership and empowerment

People with learning disabilities need to be included in the debates that shape how they are talked about if they are to feel empowered rather than demeaned. Therefore it is essential that terms and definitions are accessible. Complex diagnostic language acts as a barrier to understanding the meaning of terms making it difficult for people to understand and challenge the label given to them. Davies and Jenkins (1997) contended that people with learning disabilities have an awareness of the 'social category of disability' through everyday interactions and relationships but do not have access to professional labelling discourses. A group that appreciates how it comes to be labelled and the meaning and impact of that label can seek ownership of it; though this is fraught with difficulties (Finlay and Lyons 2005). It is then possible to challenge stigmatisation and discrimination as well as those who do the labelling. Self-advocacy groups have been invaluable in this process so far but there is a responsibility for professionals to share the power they have to define and describe populations and determine their experience.

In the interests of accessibility we would like to summarise these points in plainer English:

Plainer English Summary

- We think the questions that Simon Whitaker asked are very important
- We think that the most important thing is the way people like psychologists, nurses and social workers talk about groups of people with learning disabilities rather than just the name they give to the group
- We think the term 'people with learning disabilities' is OK as long as those people are talked about with respect and as valued members of the community
- We think that 'learning disability' is just a name, a label that is given by professionals (like psychologists and doctors). It doesn't say much about what a person is really like.
- We think that professionals need to use plain English so everyone can understand what 'learning disability' can mean and how the label gets given to people. Then people with learning disabilities can say what they think about this and together we can find better ways of talking about people.

N.B The author would welcome further discussion from readers on the points raised by this article.

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